

# SPIRITUAL CARE FOR PEOPLE SUFFERING FROM DEMENTIA DISORDERS – SELECTED ISSUES

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A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

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## ABSTRACT

Spirituality as an integral part of human life has a significant impact on the understanding of disease, reactions associated with it, and decisions made in the treatment process. Therefore, it is important for effective therapeutic and care management. Spiritual care constitutes an important element of holistic nursing care focused on the needs of patients with dementia in cooperation with the therapeutic team, and it prevents depersonalisation of the patients, taking into account their psychosocial needs. Progressive dementia affects human functioning in terms of basic everyday activities and the possibility of self-care. If the care is focused solely on satisfying the patient's biological needs, it often becomes task-oriented care and depersonalises the patient's individuality, whose psychosocial needs are not taken into account. The knowledge of spiritual aspects of the patient's functioning allows these issues to be included in the care and treatment plan, thus enhancing the effectiveness of the therapeutic process. Spiritual care is a valuable and integral element of holistic care, emphasising the broader aspect of humanity, and the recognition of spiritual needs alongside physical, social, and emotional needs involves the commitment and cooperation of all care providers. The aim of this paper was to present selected issues of spiritual care provided to patients suffering from dementia disorders. Selected issues were presented on the basis of available literature analysis. The approach to the individual needs of patients emphasises the holistic dimension of care. Spiritual care should be provided by the therapeutic team at every stage of contact with the patient.

**Key words:** dementia, spirituality, spiritual care.

## INTRODUCTION

The holistic concept of health takes into account biological, social, cultural, as well as emotional and spiritual dimensions of human functioning. In the provision of care, spirituality is often overlooked, which has an extremely important impact on patients' activity and their broadly defined bio-psychosocial well-being [1-3]. The spiritual dimension of human existence significantly influences the concept of health, coping with disorders, chronic disease, and disability [4].

Spirituality is perceived as one aspect of humanity which relates to the way people seek and experience the meaning and purpose of transcendence. It also includes the relationship between a person and him/herself and those he/she considers meaningful or sacred [5]. Spirituality can also be understood as the ability of people to achieve individual fulfilment, to give meaning and purpose to life [6].

It is the duty of the therapeutic team to care for patients with regard not only to their biological condition but also to the psychosocial, spiritual, and existential aspects of their functioning [7]. Numerous studies show an important relationship between spirituality and overall quality of life, coping with disease, and recovery [4, 8-11]. Spirituality influences the patients' understanding of disease and their reaction to it, as well as decisions resulting from the implementation of therapeutic recommendations [1, 12]. Consideration of the spiritual dimension of human functioning is a key element of professional care in a practice focused on the patients' needs [5, 13] and respecting their beliefs and values [14]. Knowledge of the spiritual aspect with regard to the patient's functioning allows the supplementation of the care and treatment plan, and it increases the effectiveness of the therapeutic process [7, 15]. The provision of person-centred care facilitates the implementation of

therapeutic recommendations also for patients with dementia [16]. Selected issues are presented herein on the basis of the literature analysis available in the Medline PubMed database.

The aim of this paper is to present selected issues of spiritual care provided to patients suffering from dementia disorders.

## DEFINITION OF SPIRITUALITY

The definition of spirituality and spiritual care is related to the transformations facing modern societies. These transformations lead to the development of diverse individual spiritual, religious, and cultural needs of individuals [17]. The perception of spirituality as an important factor influencing the overall functioning of the patient was initially associated with palliative care and its concept of holistic care [4]. Along with increased interest in the role of spirituality in other areas of professional practice, actions were taken to define spirituality and include this aspect in the daily care of patients [5, 18, 19].

The establishment of a uniform definition of spirituality is difficult due to the diverse understanding of the essence with regard to this term. Spirituality can be understood and expressed in different ways, depending both on the culture and tradition in which the individual functions and on their individual beliefs and needs. The role and influence of family and loved ones as well as communities on the individual's spirituality may be perceived differently [5, 20]. According to the definition developed by the European Palliative Care Association, spirituality is a dynamic and inseparable aspect of humanity, through which people seek the ultimate meaning, purpose, and transcendence, and experience a relationship with themselves, their family, others, the community, society, nature, and significant or sacred persons. Spirituality is expressed through beliefs, values, traditions, and practices [5, 20]. According to the Polish Society for Spiritual Care in Medicine, spirituality is a dimension of human life which is a reference to transcendence and other existentially important values [21, 22]. It includes the religiousness of humans (especially their relationship with God) and the customs, practices, and community life. Another aspect of spirituality is the existential search, which is particularly related to the meaning of life, suffering, and death, as well as the answer to questions about the identity of the person and his/her dignity. The existential search also refers to the sphere of freedom, responsibility, hope, and despair, as well as reconciliation and forgiveness, and love and joy. The last defined dimension of spirituality includes values relevant to humans, their relationship with themselves and with others, their relationship with work, nature, art, and culture, and the choices made in the sphere of morality, ethics, and everyday life [21].

Spirituality, in the common sense, is often identified with religiousness, which can contribute to the rejection of spiritual care by those who identify themselves as unbelievers [5]. However, it is important to remember that spirituality is a multidimensional phenomenon, not limited to the aspect related to the individual's religion or religiousness [9, 23, 24], and spiritual needs are not only related to religious or existential issues. In practice, it is often difficult to define a patient's religious, existential, or psychosocial needs. The interpretation of whether a person's particular need is considered spiritual depends on individual attitudes, beliefs, worldviews, and social and cultural conditions [25]. It is important to consider the spiritual aspect of care for all patients, whether or not they identify themselves as religious persons [26], and spirituality should be broadly defined to include the religious, philosophical, existential, cultural, and personal beliefs, values, and individual preferences of the patient [5].

## IMPLEMENTATION OF SPIRITUAL CARE

Traditionally, chaplains are called on to handle the spiritual aspects of a patient's functioning [5], but spiritual care, within the limits of their competence, should be carried out by all members of the therapeutic team at every stage of contact with the patient. The recognition of spiritual needs among the coexisting physical, social, and emotional needs requires the involvement and collaboration of all care providers [5, 7, 22, 27, 28]. Understanding the patient's spirituality is an integral part of care [12], and the identification of spiritual suffering is as important as recognition of physical ailments. Therefore, each member of the therapeutic team should see the patient as a holistic entity, functioning in many dimensions [7].

In the provision of care, it is important to show the patient a compassionate presence and to support the patient in all aspects and dimensions of their struggle with the disease. A key role is given to the patient's narrative that expresses their fear and pain, but also their hopes, desires, or dreams. It is advisable to enable patients to carry out spiritual practices [12, 23], as well as to ensure contact with a chaplain when the need is expressed [12]. It is important that spiritual support is readily available, even if patients do not expect it at any given time, and that the staff are guided by a sense of sensitivity in recognising patients' spiritual needs [29].

The inclusion of spirituality issues in the diagnosis and psychotherapeutic process as well as in patient care is an example of the implementation of a person-centred care concept that takes into account the diversity of individual needs [7, 22, 30, 31]. Spirituality issues are also often addressed by the patients or result from their current disorders [31].

The key assumption of a spiritual concept is to refer to the subjective experiences and patient's needs, their sense of dignity and uniqueness [22], as well as the cultural and social conditions in which they function [30, 32]. In view of the above assumptions – openness, authenticity, compassion, and the underestimation of patients are identified as fundamental behaviours necessary for spiritual care [9, 33].

Recognition of the patients' spiritual needs can be based on questions about the essence of spirituality and religiousness as well as their impact on their current situation. It is also relevant to determine whether the patient feels the need for his/her spiritual beliefs and related practices or values to be incorporated into the therapeutic and caring process [4]. A comprehensive and structured tool for the identification of spiritual care needs with the patient about his/her spirituality is the FICA questionnaire (Faith and Believe, Importance, Community, Address in Care) [34]. The FICA covers 4 areas related to patient spirituality. The first area concerns the interpretation, essence, and meaning of spirituality in the patient's life, while the second allows for understanding of how the patient's beliefs affect his/her life, health, and coping with the disease. Then the patient's affiliation to a particular community (spiritual, religious, or community with which he/she shares beliefs) is analysed, and whether this affiliation supports him/her. The last part of this questionnaire includes questions about the patients' expectations as to how to fulfil their spiritual needs in the therapeutic process [4].

Spiritual care is a form of person-centred care that takes into account the subjectivity of patients with dementia in every dimension of the care provided [35, 36]. This approach is a specific response to the reductionist and biomedical perception of dementia, which focuses on the incurable disease unit and ignores the patient's personal values, experiences, and beliefs [5, 24, 35]. The concept of person-centred care indicates that medical and caring staff treat a patient with dementia as a person with experience, life history, and self-esteem. These individuals, despite progressive cognitive deficits and, consequently, limitations in their daily functioning, have full rights like every patient. It is the staff's task to understand which caring and therapeutic treatment will be most beneficial to a person with dementia from their point of view. For this perspective to be achieved, it is necessary to involve the patient (to the optimal extent) and his/her relatives in co-deciding the care process [36].

Spirituality is an important source of coping with the disease among people suffering from dementia, especially in the early stages, thus it is important to recognise the beliefs, faiths, traditions, as well as the spiritual needs of patients and to enable them to practice the rituals that are important for them. Understanding the role of spirituality in the individual

needs of patients is a basis for developing a care plan aimed at improving quality of life [24, 37].

Spiritual care should be part of holistic, patient-centred care provided by nurses [24, 33], but this type of care provided to people with severe dementia is challenging. Due to the increasing cognitive impairment, patients have difficulties in communicating with their environment and therefore do not verbalise their needs, including spirituality. In addition, they often suffer from numerous coexisting conditions that exacerbate disorders resulting from the underlying disease [38, 39]. Consideration of spiritual needs in the care of patients with dementia is necessary to maintain their proper functioning [24]. Such care should not only focus on decreasing autonomy, but should include self-perception, health, and the inevitability of time [25]. The ability to understand the spiritual needs of older patients with dementia is a challenge for care providers. Meeting these needs in nursing care reflects a person with dementia as a valued person and supports their personal philosophy of life [40].

Available studies indicate that elderly people with dementia who are permanently in care institutions often have special spiritual needs, which in most cases are not recognised [24, 39]. In addition, progressive dementia may cause spiritual suffering, which may increase the feelings of loneliness and anxiety [37, 39]. This suffering is associated with poor quality of life, fear of death, and dissatisfaction with care [9], and therefore the provision of spiritual care, especially at the end of life, is perceived as extremely important in maintaining high-quality care. Spiritual pain experienced by patients and family members has an impact on many aspects of the disease, including physical and emotional symptoms, social relationships, and overall quality of life [41].

The issue of spiritual care provided to dementia patients is not a common topic of research [24, 35, 37, 38], but the available research results indicate that taking into account the spiritual and religious needs of people with dementia may be important in ensuring their well-being [25, 39, 42] and in minimising the risk of unwanted behaviour [24, 38].

In the early stages of dementia, patients are able to express their preferences for incorporating spirituality into everyday care. With the progression of disease symptoms, care increasingly relies on recreating the patients' prior will, showing sensitivity, and interpreting their expressions and non-verbal forms of communication. For patients with severe dementia, it is advisable to provide care in accordance with their preferences, habits, and previous wishes expressed before the loss of communication [24, 38, 39]. In the opinion of nurses and caregivers, among patients with severe forms of dementia, self-esteem, which is the basic area of spiritual care, can be achieved by refer-

ring to the patients' life achievements and manifesting active listening as a communication strategy [43].

A key element in the provision of spiritual care to patients with dementia according to the concept of person-centred care is to know their life history. Past information is helpful in the implementation of holistic care and provides guidance for interpreting current patient behaviour [35].

Nurses can provide support and spiritual care by incorporating these issues into their daily patient-centred nursing care through active listening, authentic presence and openness to others, and a therapeutic touch [26, 39, 42, 44]. However, in one of the available studies, the nurses confirmed that they lacked knowledge about spiritual needs, and the understanding of dementia patients' spiritual needs as well as how to realise them was intuitive. The intuitive approach, which gave greater sensitivity to the patients' needs, was associated with the nurses' experience of working with people with dementia [39]. The nurse's understanding and acceptance of the patient's spiritual needs avoids disregard for the patient and creates a space necessary to carefully listen to the individual's spiritual perspective, observe, and draw attention to circumstances that provide spiritual, inner peace. According to some professionals, the best way to understand spirituality is to know a person's religion and spiritual practices [45].

Some studies confirm that spiritual care is part of the nurse-patient relationship and that a joint faith enables discussion on topics such as life, death, pain, and health. However, the importance of the ability to communicate regardless of religious aspect should be emphasised. In the patients' opinion, the experience of nurses was a factor that allowed for a greater ability to engage in dialogue about spirituality [46]. Other research showed that nurses, by respecting patients' spiritual beliefs, cultural and religious values, and taking into account the ethical aspect of care, can create conditions conducive to patients' spiritual development. Moreover, their perception of spiritual care influences its quality [33].

Forms of spiritual care provided by nurses also include the collection of patient information, religious counselling, as well as assistance in maintaining family ties, maintaining relationships with the environment, and discussing problems arising from the end of life [47]. An important role in the spiritual care of patients with dementia is played by sound stimuli (music), evoking important experiences and experiences (reminiscence therapy) and sensory stimulation [35, 38, 39]. The involvement of the patient's relatives in maintaining family and social ties and practicing cultural traditions also has a positive impact [35, 39, 48, 49]. Spiritual care is also understood as all activities undertaken in relation to the daily facilitation of patients' spiritual or religious needs and the experi-

ence of transcendence [24, 39]. With appropriate assistance, a person with severe dementia is able to engage in spiritual practices [50].

Proper and conflict-free relationships and communication between patients and staff to provide a good atmosphere are also important elements of spiritual care. Proper communication, both verbal and non-verbal, should be adapted to the patient's needs and severity of dementia. It is necessary to respect the patient's preferences and boundaries, including physical ones, such as acceptance of various forms of touch or organisation of everyday life. The social inclusion and integration with other patients also require the individual's acceptance [39]. A positive element in the provision of needs-based care for patients with dementia is additionally the personalisation of their environment, which according to their preferences and habits may contribute to slowing down the degradation of cognitive activities and improving relationships, behaviour, and mood [35].

The progressing dementia process, due to cognitive dysfunction and often coexisting mobility difficulties, usually limits the possibility of continuing existing religious practices. However, those declaring to be believers who have carried out religious practices before their dementia usually want to continue them. Faith and spiritual practices can help patients to find hope and come to terms with progressive disorders [37]. In addition, religion understood as participation in community life is important for people with dementia to maintain their identity, affiliation, and social contact [35, 37].

## SUMMARY

Spirituality represents a part of human life, and spiritual care is a valuable and integral element of holistic nursing care focused on the patient's needs after a dementia diagnosis.

Progressive dementia limits the patients' functioning in terms of basic everyday activities and self-care possibilities. Therefore, such care includes, above all, satisfaction of physical needs. However, the care provided to these patients must not focus solely on the physical dimension of functioning but should also take into account the wider aspect of humanity. The basic needs of people with dementia include psychosocial needs, a sense of security, belonging, acceptance, respect, self-esteem, and maintaining social relationships. Care focused mainly on meeting the patient's biological needs often becomes task-oriented and depersonalises the patient's individuality.

Recognition of the patient's spiritual needs among coexisting physical, social, and emotional needs requires the involvement and collaboration of all care providers [4, 7, 22, 27, 28]. Understanding the patient's spirituality is an integral part of care [12],



and the identification of spiritual suffering is as important as diagnosis of physical ailments.

The ageing of population and the increasing number of people struggling with chronic diseases are causing an increasing focus on alleviating ailments, suffering and pain resulting from causes other than somatic dysfunction. However, for therapeutic and caring treatment to have the desired effect, it is necessary to try to understand how the disease affects the patient also in the spiritual dimension.

## CONCLUSIONS

Spirituality, as an individual patient's need, is an important source of coping with the disease by people, especially in the early stages of dementia.

The care of dementia patients in the spiritual aspect is necessary and highlights its holistic dimension. It should be provided by the therapeutic team at every stage of contact with the patient.

Nurses, who have the most frequent contact with people suffering from dementia should express particular sensitivity and a holistic perception of patients also in the spiritual dimension of their functioning.

It is advisable that issues related to the implementation of spiritual care should be included in the primary and postgraduate education of both nurses and other medical personnel.

## Disclosure

The authors declare no conflict of interest.

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